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PRACTICE POINTER

Adapting to transparent medical records: international experience with "open notes"

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What you need to know

- By 30 November 2022, patients in England who have signed up for an online service such as the NHS App should have prospective access to their primary care health record enabled by default. Access includes GPs' free-text consultation entries (commonly referred to as open notes)
- GPs may have concerns about open notes, a practice that has now been implemented in several countries. To date, preliminary findings show that many reported worries disappear with experience.
- Doctors can empower patients and themselves by implementing a number of techniques and practices in preparation for patient access to their notes.

By 30 November 2022, patients in England who sign up for online services such as the NHS App[1] should have access to their full primary care health record prospectively and by default.[2 3] Every new entry made in the primary care record will be immediately visible to patients, including the free-text consultation entries (commonly referred to as "open notes").

Clinicians are understandably concerned about this radical change in practice, fearing additional burdens for their work, an onslaught of calls or emails from anxious or confused patients, and potential risks to patients' safety.[4 5]

With this change, the functionality of the clinical record is also evolving.[6-8] No longer will the medical record serve primarily as an aide memoire or communication tool for clinicians, or as a billing device (as in the US), it will transform increasingly into a central form of communication among clinicians, patients, and, in many cases, their care partners. In this article, as a team of primary care physicians (BM, TD), a patient (LS), health services researchers (TD, BM, GD, CB), social scientists (BM, GD), and a philosopher (CB), we draw on ongoing qualitative work (by BM, GD, and CB) among primary care staff in England and combine it with evidence from countries where open notes are advanced (see table 1) to summarise concerns and offer suggestions for how clinicians may consider changing their practice.

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Table 1 | Clinicians' concerns about open notes and current evidence

Clinicians' concerns	Evidence
Open notes will add to workload and increase inefficiencies	NHS Digital stated: "Early adopter sites [in England] reported that, when switching on prospective access for their patients, they did not see an increase in workload."[9] In a recent US study of 116 primary care physicians, 69%, before adopting open notes, anticipated spending more time addressing patients' questions outside of consultations. After implementation, only 8% reported having done so.[10] Such findings are similar to those in prior studies,[11] but in another recent US survey, 62% (n=485) of physicians reported spending the same amount of time writing notes after patient access was enabled, whereas about a third reported taking more time.[12]
Access could have complex implications for patient safety, especially for patients at particular risk	When and how clinicians can appropriately redact information without contributing to stigmatisation or harm is a difficult issue for practices.[13] Some suggest it may be resolved by adapting current software architecture to support clinicians' discretion about how to prevent harm.[7 14] Clinicians in Sweden and the US report recording two entries in situations where patients or third parties are at risk of serious physical harm (such as a vulnerable patient in a coercive relationship who has shared information): one for the patient, and another for clinicians. In September 2022, NHS Digital reported that "Early adopter sites [in England] were asked to report immediately any clinical safety incidents or near misses, lessons, risks and issues and concerns," and "No incidents or near misses have been reported to date by early adopter sites."[9] Access to notes may function as a safety mechanism.[15-17] In a multicentre survey in the US, among 22 000 patients who read their notes, one in five reported an error, and 40% of those patients perceived the error to be serious.[18] Their reports included inaccurate medical history and diagnoses, wrong patient's notes, and wrong-sidedness.
Patients may be harmed emotionally by what they read, and this could affect their behaviour	Evidence of emotional harm is lacking; in the largest survey of open notes in the US, involving more than 22 000 patients in three diverse health systems (response rate 22%), most (16 354/22 520, 73%) reported that access was very important for helping take care of their health.[19] Two thirds of those taking medications who read at least one note in the previous 12 months reported greater understanding of their medication regimen, and 14% of those surveyed reported improved adherence,[20] a figure that rose to 20% among patients diagnosed with serious mental health conditions.[21] An underappreciated consideration may be anxiety and confusion caused by lack of ready access to notes.[7 22]
Documentation will be "dumbed down," reducing its clinical value	Reports assessing whether changes in documentation accompanying open notes diminish their value to other health professionals have not been published,[23] but in a US survey, 77% (n=188) of primary care physicians perceived no change in the value of their notes for other clinicians.[12]
Patients will feel judged or offended by what they read, thereby undermining the patient-doctor relationship	Some patients report access to notes builds greater trust. Dr Amir Hannan, successor in 2007 to the practice where Dr Harold Shipman worked, found that offering patients access to open notes helped establish a "partnership of trust."[24] In a three-centre study in the US, most patients reported unchanged or increased trust in their doctor after reading their notes, and many described enhanced teamwork and shared goal alignment with their clinicians.[25] However, in the same study, 2411 patients (10.5%) reported feeling judged or offended by something they read.[26] They described feeling labelled and/or disrespected, or finding something surprising or erroneous in a note. In other single-centre qualitative studies, patients who report discrepancies between what was discussed during appointments and what was later documented also indicated strained trust in their clinicians.[27 28]
Patients will contest or disagree with their notes	Research into patients directly contesting or disagreeing with their notes is limited. In a US survey, among 4500 survey respondents who read at least one medical note during a 12 month period, about a third reported that checking for accuracy was the principal reason for reading their notes.[29] Among the 7% (331/4592) of patients who reported contacting their physician's office about a note, 29% perceived an error, and 85% of these respondents were satisfied with its resolution.
Access will increase risk for litigation	We are aware of no medical malpractice cases that have arisen in the US because of open notes. If clinicians make changes that reduce the quality of documentation and lead to error, risks of malpractice suits might increase.[30] However, if patient access helps reduce errors or diagnostic delays (the leading causes of claims[30-32]), this could reduce the risk of malpractice suits.
Health inequities will become be magnified	In several US surveys, patients who are older, less educated, who identify as being from racial or ethnic minorities, or whose first language differs from their provider are less likely to use online record access platforms.[19 33] However, when patients from these demographic groups gain access to notes, they report greater benefits from shared notes than do their counterparts, including increased trust and teamwork.[19 29 34 35] In the US, recent analyses indicate that negative patient descriptors in notes are significantly more common for non-Hispanic black patients and for patients with diabetes, substance use disorders, and chronic pain.[36 37]

Background to open notes

The move to share access to clinical records signals a more equal partnership between patients and clinicians. In adopting this innovation, England follows other countries such as Sweden and the US, where both experiences of clinicians, before and after patient access, and patients' experiences with reading their notes have attracted scrutiny.[38-40] In England, since April 2019 the GP contract

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committed practices to offer full online access on a prospective basis to new patients—that is, from the date patients request it.[41] Notably, by July 2022, 48.1% of patients had signed up for at least one service, but only 13.7% were able to view their detailed coded record.[42] Information regarding the percentage of patients with full access to their records—including free-text consultation entries—is not publicly available, but currently the level of access granted varies and is a source of frustration for patients.[43]

Clinicians' concerns

As movement towards transparency accelerates in different countries and health systems, surveys and qualitative studies show primary care staff share many questions about the practice of open notes. These concerns seem to cut across national boundaries and health systems.[4 5 10 44 -50]

Table 1 summarises concerns commonly raised by clinicians, and the current evidence for each of these. These findings come with several caveats. They focus on the perceptions of clinicians and patients who use open notes, and findings dependent on self reporting can be unreliable. The data draw primarily on small numbers of medical centres and hospitals, limiting the generalisability of the results. Moreover, the findings may over-represent respondents with positive or negative biases about patient access to clinical notes.

More robustly representative surveys and studies that include objective measures of the effects of open notes on documentation, clinician workflow, and patient outcomes have yet to emerge.[23 51 52] From both patient and clinician perspectives, many challenges and unknowns persist, and it will be crucial to learn more about the consequences of shared notes as more experience emerges. Notwithstanding the many uncertainties, there have been increasing calls for healthcare to follow other industries in offering consumer or client transparency. The NHS decision to increase transparency may also be influenced by the participatory design movement in the Nordic countries—often termed "the Scandinavian approach"—which emphasises the value of democracy and democratisation in digital design.[53 54]

Recommendations to prepare for open notes

Drawing on earlier published recommendations, recent research, and patient and clinician experiences with open notes, we offer 10 suggestions to help GPs, the wider primary care team, and patients prepare for this change of practice.[4 13 55 -64] Reviewed and informed by a panel of six patients (see "How patients were involved in the creation of this article"), these recommendations are designed to help physicians optimise the potential benefits of open notes and minimise their risks (see also box 1, a guide for patients, and box 2, what patients find helpful). In the future, undergraduate medical education, GP training programmes, and continuing medical education will likely cover this innovation. Brief educational interventions may also help clinicians and patients become more confident and comfortable with open notes.[55 56]

Box 1: A guide for patients before reading online medical notes

- You may benefit from reading your notes. In studies, patients who read their notes reported feeling more empowered, more in control of their care, and working better as a team with their doctor.
- Reading your notes may help you better understand your health. Patients also report that reading their notes helps them to remember their care plan, understand the reason for treatments, and to follow up on next steps.
- To feel better prepared for appointments, consider reviewing your own notes before and after a GP appointment.
- Clinicians sometimes use acronyms/abbreviations in notes. Here is a list of common terms [*Insert a list of especially common standardised terms*].
- To err is human, and sometimes GPs make mistakes in records. We encourage you to check your notes for accuracy. [*Insert advice on the practice's protocol for communicating perceived errors, including who and how to contact the practice using digital and non-digital methods of communication*]. By doing this you can partner with your GP to improve the safety of your care.
- At times, you may feel anxious or upset by what you read. Feel free to decide not to read your notes.
- People other than your GP, such as other clinicians or, in special circumstances, family or informal caregivers, may contribute information to your health record.
- For your own privacy and confidentiality, we recommend that you adopt safe practices around password protections, especially on shared electronic devices.
- Your practice is committed to maintaining patient information privacy, security, and confidentiality. However, you are in control and have the option to request your GP to switch off record access any time, if this is what you would prefer.

Share details with patients about any practice-initiated discussion aiming to increase understanding, and address queries by leveraging Patient Participation Groups.

Information should be available via leaflets and practice websites, and with hyperlinks to publications, where appropriate. Where textual communication might be an issue for some patient populations, guidance could be offered via sound podcast or infographic options.

Box 2: What patients find helpful about open notes

"I think my notes are incredibly valuable, and I read most of them (but not all of them). I use my notes to remind me of what was discussed during a visit, and they often fill in details I missed. Sometimes I refer to my notes months later and have used them to settle disputes at home ('What did the doctor say again?'). There isn't a single thing in my notes I don't understand or can't figure out from context because I was there when the note was written. And now that I have been reading notes for a few years, I believe I have become a better patient because I can see myself through the eyes of my doctor."—*Liz Salmi, female patient, aged 43, USA*

"I think most patients are more harmed by not being able to see their open notes. While it is not a primary care office that did this to me, I have been unable to see my original note from a surgery because the physiatrist [physical medicine and rehabilitation doctor] deemed me 'too fragile.' I appreciate that there are rare occasions when it may be important to hide notes from patients. However, for the most part, access is important to build trust, and I strongly believe blocking information is damaging toward the patient-doctor relationship."—*Female patient, aged 50, USA*

"I have a good relationship with my GP, but I can see open notes being especially useful in two situations: when locums are employed, so that I can check they've understood my situation, and when I have a telephone or video conference call with a medical practitioner, and I can't see what's being written and miss some of the 'unsaid' cues."—*Female patient, aged 62, Northwest of England*

"I was a bit disturbed to see what appeared to be an odd selection of entries to my medical record. My experience has been that the receptionist gives you titbits of information, and the patient has to piece it together. So, in general, I think this is a really significant positive change for patients."—*Female patient, aged 46, Northwest of England*

Educate patients and staff about open notes

- Inform patients that open notes can be empowering and can help them feel more in control of their health care.

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- Advise patients that, by actively reading notes, they may both clarify their health goals and partner more effectively with their doctor.
- Suggest to patients that reading notes may foster greater understanding of the reasons for treatments and medications and help them, their family, and other care partners to remember and follow the next steps in their care plan.
- Include links to patient information materials in the record that patients can read at home, such as https://www.bad.org.uk/patient-information-leaflets
- Share information about open notes with practice staff, including non-clinical staff, who may require training in how to manage queries from patients.

Involve patients in what you write and create a shared plan of action

- When possible, and providing there are no safeguarding concerns, turn the computer screen towards patients to show them what you are documenting, or offer to read aloud what you have written. Ask if there is anything they would like you to add.
- To ensure understanding, if you cite a diagnosis in the notes, discuss it with the patient and, where appropriate, their care giver.
- Incorporate into notes patients' health decisions and their reasons for their choices.
- Avoid directive language that may point to the role of an authoritative doctor; such as "Patient was told to...," "I have instructed her to do..."
- Use second person voice to reflect collaborative decisions; such as "We will work together as a team," "We discussed..."
- Use notes to celebrate patients' strengths and progress; such as "Congratulated on stopping smoking." When addressing areas in which patients may feel they are failing, balance the discussion with positive statements.

Write entries with empathy and sensitivity

- Assume that patients read their notes, even if they do not discuss what they have read in consultations.
- Avoid medical jargon or potentially offensive acronyms. For example, use "follow-up" instead of "F/U"; "shortness of breath" instead of "SOB." Where available, use inbuilt software tools to convert acronyms to full text.[65]
- Avoid references to patients that may be perceived as judgmental or offensive; such as "Patient non-adherent/complaining about/denied/stated/refused."
- Discuss or avoid potentially difficult terms. For example, for patients with obesity, omit or place that word in the context of body mass index and health risks, rather than as a sole descriptor that may be viewed as pejorative.
- Avoid stigmatising or discrediting language, including reference to patients' diagnoses or health status (such as "drug user") or to their progress or demeanour (such as "he insists that," "in denial," "difficult patient," "failed to").

Explain that free-text entries serve multiple functions

- Explain the multiple purposes of the medical record to patients.
- Although patients will now read their notes, do not leave out appropriate differential diagnoses. Discuss your logic and sense of probabilities with them. Strive to ensure that patients are not surprised by what they read.
- Encourage patients to ask about entries they may not understand.

Address risks and possible unintended consequences.

- During consultations, talk about diagnostic possibilities with patients. For example, "It's extremely unlikely that this is a cancer, but we wouldn't want to miss it, so I'm adding it to my list of possibilities. It's far down my list—it's much more likely to be X."
- Discuss with patients the emotional risks versus benefits of reading their notes. Some may decide not to read them, thereby avoiding potential upset.
- Talk to colleagues about best practice regarding safeguarding and confidentiality. Set up a protocol for practice staff to follow if patients report upset or anxiety.

Support marginalised populations

- Do not assume more vulnerable or disadvantaged patients will not benefit from, or "handle," reading their notes.
- Consider what steps your practice can take to maximise accessibility and inclusion. For example, offer "How to get online" guides to the practice website. Work with local charities and patient participation groups to provide additional local support.

Offer help and advice about proxy access, safeguarding, and privacy

- Advise adolescents and at-risk individuals about the importance of privacy and confidentiality.
- Safeguard against revealing third party information by advising patients you can use a separate and hidden entry to record sensitive information they would prefer not to be visible in their online record.
- To protect the privacy of their records, remind patients to adopt safe practices around password protections, especially on shared electronic devices.
- Inform patients they can ask their GP to turn off open access, so that only their GP and other clinicians can view their record.
- Offer advice and reassurance about maintaining privacy via the practice website, surgery posters, and in person.

Ask patients for feedback and manage disagreement at the earliest opportunity

- Do not assume that, without active encouragement, patients will be comfortable offering feedback on perceived errors in the medical record.
- Be open about the fact that errors and omissions can happen in records. Be proactive in encouraging patients to help spot errors so they can be rectified.
- Create a practice protocol for processing disagreements.
- If disagreements are not resolved, ask patients to work with you to document their view as an additional note. For example,

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"Discussed difference of opinion. [Patient's name] would like me to note that..."[66 67]

Remind patients to check their records before and after appointments

- Encourage patients to review their notes before visits, both to refresh their memory and to be prepared to discuss any concerns.
- Add reminders to do this via the practice website, surgery posters, and in person.
- Incorporate reminders to patients to read records via GP phone messaging systems, and/or integrate such reminders into text messages about appointments.

Raise awareness of open notes

- Do not assume patients know they can access their primary care records online.
- The consultation is the most powerful place to inform patients about open notes.
- Advise patients where they can learn more about the NHS App and other platforms they can use to access their notes.[67]
- Adapt the illustrative patient guidelines to your practice (box 1) and adopt other methods to publicise online access via the surgery website, and by posters and leaflets in waiting rooms.

How patients were involved in the creation of this article

Six patients, including one who is a co-author (LS), helped in preparing this article. Reflecting combined feedback, we modified and expanded our list of recommendations for talking about and writing free-text entries, and we included box 1 (a guide for patients before reading online medical notes). Patients also offered their own comments on the paper, including their experiences and views of open notes (incorporated into box 2).

Education into practice

- Consider how you might talk to patients about access to their clinical notes. Ask what else can be done to help patients prepare for reading their notes.
- Reflect on how access could be used as a means of empowering patients and enhancing shared decision-making.

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